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Developing Person-Centered, Interactive, Systematic, Effective Rehabilitation (PISER) for Persons with Parkinson's - The Outcomes of a Pilot Intervention

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Abstract

Aim: To describe the development and outcomes of a rehabilitation intervention for persons with Parkinson's and their near-ones. **Material and methods**: Customer-understanding-based intervention development; and a pilot study: a random sample of persons with PD (n=18) and their near-ones (n=7) were divided into subgroups: Persons with PD, Gym rehabilitation; Persons with PD, Home rehabilitation; Near-ones, Gym rehabilitation; Near-ones, Home rehabilitation. Data included clinical measurements, scores from a PDQ-39 questionnaire and a simple diary, analyzed with descriptive statistics. **Results:** The PISER intervention was established to be feasible in relation to study and data collection procedures, outcome measures and to recruitment of persons with PD. After the eight-week intervention, both Persons with PD subgroups and Near-ones in Gym group had better clinical outcomes and better emotional, social and communicative health-related quality of life. Near-ones, Home rehabilitation had marginally poorer clinical outcomes, but still reported better cognitive well-being. **Conclusions:** The PISER intervention was shown to be feasible. By engaging in systematic physical activity, persons with PD and near-ones maintained or developed their functional capacity, psychosocial well-being and certain aspects of health-related quality of life. An eight-week rehabilitation intervention had a positive impact on self-management, especially in gym-groups, in which the participants enjoyed the social aspects of group rehabilitation and received individual instruction and feedback during physical activity. This kind of person-centered, systematic physical activity intervention may prevent inactivity and fall risks, and delay onset of activity limitations. It is vital that healthcare professionals and clients with PD together analyze and discuss the meaning of physical activity and self-rehabilitation.

Keywords: Parkinson's disease, Rehabilitation, Person-centeredness, Intervention, Pilot, Feasibility.

Introduction

Parkinson's Disease (PD) is the second most common age-related neurodegenerative disorder after Alzheimer's disease. To date, approximately ten million persons throughout the world have been diagnosed with PD, and the majority are males aged 55 or older [1,2]. There is no single known cause of PD, but some genetic and environmental factors have been identified [3]. Despite the disorder's chronic nature, the age and mode of onset, prominence of symptoms, rate of progression and resultant degree of impairment differ greatly between individuals.

The diagnosis of PD usually occurs after an extended period of time, because the disease includes an initial asymptomatic phase followed by a non-specific, prodromal phase. At the time of diagnosis, persons with PD can already be experiencing severe limitations in Activities of Daily Living (ADL) and a decreased Quality of Life (QoL), and are thus in immediate need of rehabilitation [4]. If rehabilitation is started immediately, and especially if the care and rehabilitation given are systematic, holistic, person-centered, and inter-professional, persons with PD can achieve a similar QoL as same-aged individuals without PD [5]. Still, to achieve such benefits from rehabilitation, persons with PD need to develop long-term exercise habits. It is beneficial to take individual preferences into account, because a person is most likely to continue with an exercise regimen if it is enjoyed [6]. Intrinsic motivation is also important for long-term adherence [2].

Not only persons with PD but also their near-ones (i.e., spouses, other family members) can experience strain and a poor QoL [7,8]. Researchers have seen that at-home rehabilitation becomes safer and truly person-centered when near-ones are involved [6]. However, rehabilitation still primarily occurs outside the home and without the

inclusion of near-ones, even though a home setting is suitable for the majority of rehabilitation activities [9]. The aim of this study was to develop a person-centered, interactive, systematic, effective rehabilitation intervention for persons with Parkinson's and their near-ones. In this article, we delineate and present the pilot intervention, its´ feasibility and outcomes.

Background

Parkinson´s disease is a multifaceted, neurodegenerative, chronic disorder affecting both motoric and voluntary movements, such as dual-task performance or gait. The cardinal signs of the disease, e.g., tremors, rigidity, bradykinesia and postural instability, are caused by a loss of dopamine in the substantia nigra and associated nigrostriatal denervation. PD is divided into two subtypes: tremor dominant and postural instability gait difficulty [1,2]. A slowly proceeding autoimmune condition, PD has five symptom-related stages. In stages 1-2, persons with PD have mild or relatively mild signs of illness, relatively good functional capacity and can independently manage everyday life. In stages 3-5, persons with PD experience severe or very severe symptoms, impairment in functional capacity and have an evident need for assistance and help [10]. Through an active physical lifestyle and medication, PD symptoms can be alleviated and a person's functional capacity maintained or improved [1], especially for those with early- or mid-stage PD [6]. However, for older persons, meaning in everyday life and QoL are often more important than ability or disability per se [11]. Parkinson´s disease also affects non-motoric functions, e.g., task initiation and accomplishment, cognition, social skills, sleep, fatigue [1] and psychological well-being [12]. Therefore, the perceived disability and health-related QoL of persons with PD [13,14] should be systematically analyzed during rehabilitation. Accordingly, an inter-professional, collaborative approach to PD rehabilitation is important [15,16].

Healthcare professionals involved with PD care and rehabilitation should act in a person-centered manner [2]. Person-centeredness can be defined as respect for a person's narratives, preferences, values and needs, in which the person's sense of self, lived experiences and relationships (i.e., personal knowledge) are reflected, and demonstrating this respect by safeguarding the partnership that exists in care through shared decision-making and meaningful activities in a personalized environment [17-20]. Person-centeredness also includes respect for a patient's autonomy and self-determination capacity. It is made concrete through a trustful relationship established during the planning and evaluation of care and rehabilitation with a patient, and should moreover include the patient's near-ones [21]. It is important to encourage near-ones to play a decisive role and continuously support and encourage the person with PD. Rehabilitation should be carried out in a peaceful, relaxing environment [22], e.g., in the patient's home.

The terms public and patient involvement [23] and human-centered co-design [24] are considered indicators of person-centeredness in research activities, e.g., the identification of research priorities, participation in data collection or analysis, or commenting on research reports. In a scoping review (n=67) with a focus on PD rehabilitation, the majority of studies were seen to not include patient or near-one involvement in the planning, conducting or evaluation of rehabilitation for persons with PD. Instead, the rehabilitation focus lay on physical exercise forms with or without digital devices (VR glasses, closed-loop sensory feedback, gamepads, or telerehabilitation with visual feedback) through which immediate feedback was provided. In that review, PD rehabilitation was seen to be focused on physiological symptoms and functional capacity, not cognitive or psychosocial well-being per se. While the effectiveness of rehabilitation through physical activities was difficult to synthetize, physical exercise did appear to decrease non-motoric symptoms and improve physical outcomes, ADL functions, and well-being [9].

Materials and Methods

In this study, a human-centered co-design was used. Such an approach entails an active partnership with customers (seen here as persons with PD) for the purpose of designing or improving care (see SQUIRE guidelines (https://www.equator-network.org/reporting-guidelines/squire/), service systems or programs [24]. For the purposes of this study, a service design [25] approach was applied **(Figure 1).**

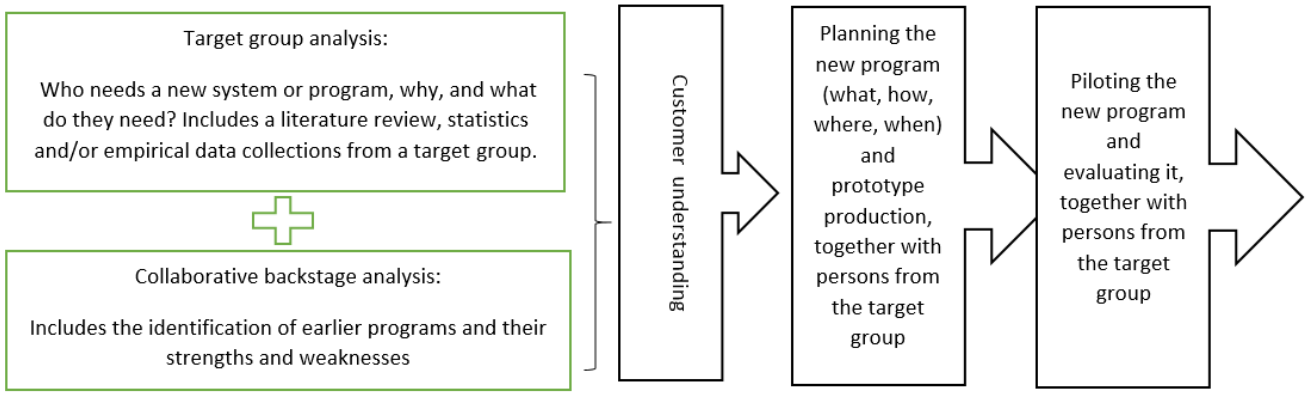

Figure 1: A service design process for PISER pilot intervention.

In Finland, there are approximately 16 000 persons with PD, but only about 60% of them belong to any PD self-advocacy group. Some years ago, persons with PD recommended the research idea investigated here to the faculty overseeing the research, which can be considered public involvement. In their comments, they noted that rehabilitation for persons with PD in Finland is quite unsystematic and that there is a singular focus on rehabilitation centers. When starting this research project, the research group sought to actively encourage persons with PD and their near-ones to express own subjective interests and needs regarding rehabilitation and be involved in the research and rehabilitation intervention design.

As part of the service design approach used here, a customer understanding process was started (autumn 2018, spring 2019). During collaborative meetings, an evolving research group comprised of members from different professions and perspectives (persons with PD, nursing researchers, registered nurses) and others (rehabilitation organization staff, digital/virtual healthcare system experts) discussed rehabilitation needs, strengths, weaknesses and possibilities. A scoping review was also conducted at the same time, to describe the existing knowledge on PD rehabilitation suitable for the home environment, with digital devices if preferred [9]. Emanating from the aforementioned meetings and the scoping review, a minor survey was conducted that included persons with PD (n=10) and their near-ones

(n=9 spouses) who had participated in a week-long rehabilitation at a local rehabilitation center spring 2019. The participants were asked to indicate their preferences regarding various person-centered physical and psychosocial rehabilitation activities available in-home or in the setting's specific geographical area. One could discern from the survey's (non-published) findings that the majority of participants were interested in weight training, gymnastics, dance or yoga, and that opinion was divided over whether these exercises should be undertaken alone in-home or as part of a group in a public setting.

Based on the customer understanding findings and an evaluation of available and realistic resources, a rehabilitation intervention called Person-centered, Interactive, Systematic, Effective Rehabilitation (PISER) was planned. During the intervention planning process, both the research group and the steering committee for a local PD self-advocacy group sought financial support for the pilot intervention. Some partners withdrew from the overall project at this phase, likely because their organizations would not financially profit from the collaboration. As a research group we were subsequently required to "re-think" the parameters of the pilot intervention, and to employ a physiotherapist.

The research group developed a leaflet to describe the rehabilitation intervention, including background, aim, timetable, voluntariness and anonymity issues. It was determined that participation in the pilot intervention would be free of charge, with all costs associated with the intervention financed through the research project. Members of the steering committee for a local PD self-advocacy group distributed the leaflet to persons with PD and their spouses in the local area, through which voluntary participants were sought for the pilot intervention during September 2019. In other words, this was a convenience sample without a priori expectations about sample sizes. The only eligibility criteria were a diagnosis of PD or the near relation to the person with PD (spouse). One steering committee member maintained a list of those interested in participating in the intervention, which took place October-November 2019 as a block for all participants.

For the pilot study, the ethical principles of the Declaration of Helsinki (2008) have been followed. All those participating in the pilot intervention gave their written informed consent. Comprised of both persons with PD and near ones, the participants were asked prior to the start of the intervention to choose whether they wished to be included in a gym rehabilitation group or implement a rehabilitation program at home. For those choosing home rehabilitation, a further choice was offered: the use of digital devices (e.g., VR glasses offering ergonomic circumstances to look the Träning på recept© training programs) or not. The participants themselves, therefore, decided on the rehabilitation setting, in accordance with own preferences and social needs instead of objective PD stage.

Prior to the start of the eight-week pilot intervention, the participants were asked to come to the local gym setting for an individual meeting lasting approximately 45 minutes. During the meeting, each participant was encouraged to formulate a goal for him/herself during the intervention. A physiotherapist conducted a standardized measurement of clinical functional capacity (M1, week zero) and instructed participants in their choice of physical activities in accordance with individual goals and the clinical measurements. Based on these, the physiotherapist created personalized rehabilitation plans together with each participant. The participants were then asked to complete a PDQ-39 questionnaire, which is a 39-item Parkinson Disease Questionnaire that measures perceived health-related QoL and ADL capacity [26]. All participants received a simple, structured diary. Persons with PD were instructed to record each physical activity (date, type, duration, whether alone or with someone) and perceived psychological well-being (five-point Likert scale) both before and after the activity. Near-ones were instructed to record own QoL, ADL capacity and physical and psychological well-being, while also understanding the challenges persons with PD face.

During the intervention, the gym-rehabilitation participants engaged in twice-weekly group physical activity at the local gym setting with a physiotherapist present and other personalized rehabilitation plan exercises. The home-rehabilitation participants engaged in twice-weekly physical activity in their own homes using the Träning på recept© training program for PD (Training with a prescription, specialized physician- and physiotherapist-developed short physical exercise films in Swedish, https://traningparecept.se/trana-med-parkinsons-sjukdom/) and other personalized rehabilitation plan exercises. At the mid-point of the intervention, new physiotherapist-participant discussions were held by telephone, during which positive feedback and further instruction was provided. At the end of the intervention, a last physiotherapist-participant meeting was held, during which the participants' clinical functional capacity was re-measured (M2, week eight), and the participants once more completed the PDQ-39 questionnaire and donated their diaries to the research team for further analysis.

Due to small subsample sizes, the data were analyzed with descriptive statistical analyses on both the group and subgroup levels. Intergroup median, standard deviation and differences could not be measured. The missing data can be seen in Tables 1 and 2.

Results

A total of 25 participants participated in the PISER pilot intervention autumn 2019. Eighteen were persons with PD, of which the majority (n =12, 66%) were male, aged 53-86 years (mean 70). Seven were near-ones (spouses), of which the majority were female (n=6, 88%), aged 67-79 years (mean 71.5 years). Of those invited to join the project, eight persons with PD and ten near-ones declined to participate, which is quite usual in this age group [6]. Thus, the PISER intervention was established to be feasible [27] in relation to recruitment of participants with PD but not effective with regard to their near-ones. Four subgroups were established: Persons with PD, Gym rehabilitation (PD/Gym); Persons with PD, Home rehabilitation (PD/Home); Near-ones, Gym rehabilitation (N-O/Gym); Near-ones, Home rehabilitation (N-O/Home). No-one in home rehabilitation group chose to use digital devices such as VR glasses, which may be perceived as unnecessary or inconvenient to use, but when watching the Träning på recept© films, they used tablets or laptops.

The intervention was established to be feasible in relation to study procedures, data collection procedures and to outcome measures [27] for all participants followed the intervention scheme and its´ outcome measures. Participants in the PD/Gym subgroup (n=9) engaged in physical activity 1.48 times per day **(mean, Table 1).** The typical length of physical activity was about 44 minutes. As per their choice, the participants in this subgroup engaged in twice-weekly group physical activity at the local gym setting. Other individual exercise most frequently undertaken was utilitarian, e.g., house chores, but even group strength training, walking/Nordic walking to and from the gym was seen. Participants in this subgroup exercised mostly (53%) with others in addition to the gym rehabilitation activities in group. Their psychological well-being both before and after physical activity was rather good (mean 3).

Participants in the PD/Home subgroup (n=9) engaged in physical activity 1.08 times per day (mean), and the typical length of their physical activity was about 28 minutes. As per their choice, the participants in this subgroup engaged in twice-weekly physical activity by training according to the Träning på recept© films in own home. Other individual exercise most frequently undertaken included walking, rowing, stretching exercises, cross training and utilitarian exercise. Participants in this subgroup exercised mostly alone (80%) and their psychological well-being before physical activity was rather good (mean 3) and after physical activity very good (mean 4).

Participants in the N-O/Gym subgroup (n=3) engaged in physical activity 1.10 times per day (mean), about 42 minutes. The participants in this subgroup engaged in twice-weekly group physical activity at the local gym setting. Other individual exercise most frequently undertaken was utilitarian, but even walks, strength training in group, stretching exercises, Nordic walking, ball sports and yoga were seen. Near-ones in this subgroup exercised with others (52%) in addition to the gym rehabilitation activities. Their psychological well-being both before and after physical activity was rather good (mean 3).

Participants in the N-O/Home subgroup (n=4) engaged in physical activity 1.58 times per day (mean), about 31 minutes. However, one participant recorded that he/she engaged in physical activity only four times during the entire eight-week intervention period. The near-ones in this subgroup engaged in twice-weekly physical activity in own home by training according to the Träning på recept© films. Other individual exercise most frequently undertaken included walking, utilitarian exercise, relaxation exercises, strength training in group, and dancing. Participants in this subgroup exercised mostly alone (78%), their psychological well-being before physical activity was rather poor (mean 2) and after physical activity rather good (mean 3).

Before the intervention (M1), the clinical measurements for the PD subgroups were fairly homogenous but some differences were seen (Table 2). Regarding the Five Times Sit to Stand, the PD/Gym subgroup showed a mean of 16.67 versus the PD/Home subgroup's mean of 11.06, which could indicate that the PD/Home subgroup had weaker muscles. Also, regarding the 10 meter´s walking tests (10MWT), the PD/Home subgroup showed 0.80 versus the PD/Gym subgroup's 0.91, which could indicate that the PD/Home subgroup had slightly more problems walking. When the PD subgroups were combined, we saw that before the intervention (M1) the Timed-up-to-go, TUG (10.85), the Five Times Sit to Stand (15.63) and step length, SL (1.00) were normal, the Berg Balance Score, BBS was good (50.22), but the 10MWT was below normal (0.86). After the intervention (M2), better outcomes for all clinical measurements were seen, and the 10MWT was normal (1.06). Note that due to small sample sizes the significance tests between groups could not be analyzed.

Before the intervention (M1), the clinical measurements for the N-O subgroups were also fairly homogenous. The exception was the 10MWT, where the N-O/Home subgroup showed a higher mean, 1.28 m/sec, versus the N-O/Gym subgroup's 0.93 m/sec. After the intervention (M2), better outcomes for all clinical measurements for both N-O subgroups were seen, but improvement was especially seen for the N-O/Gym subgroup regarding the Five Times Sit to Stand (M1: 12.9, M2: 9.01), 10MWT (M1: 0.93, M2: 1.14), and SL (M1: 1.07, M2: 1.27). While the N-O/Home subgroup demonstrated slightly poorer outcomes for clinical measurements after the intervention, the differences are marginal. Clinical outcomes for the combined N-O subgroups before (M1) and after the intervention (M2) were somewhat better in comparison to the combined PD subgroups, as anticipated. Note that due to small sample sizes the significance tests between groups could not be analyzed.

Subgroup code	Physical activity per day (freq.)	Physical activity during intervention (61 days)	Typical length of physical activity	Psychological well-being before physical activity	Psychological well-being after physical activity
Persons with PD, Gym rehabilitation N = 9	R: 0-6, M: 1.48	R: 55-63, Mode 55	R: 15-90, M: 44	R: 0- 4, M: 3	R: 1-4, M: 3
Persons with PD, Home rehabilitation N = 9	R: 0-5, M: 1.08	R: 45-64, Mode 60	R: 15-90, M: 28	R: 1-4. M: 3	R: 1-4, M: 4
Persons with PD (both subgroups)	R: 0-6, M: 1.28	R: 45-64, Mode 57	R: 15-90, M: 72	R: 1-4, M: 3	R: 1-4, M: 4
Near-ones, Gym rehabilitation N = 3	R: 0-21, M: 1.10	R: 54-61, Mode 54	R: 15-90, M: 42	R: 1-4, M: 3	R: 1-4, M: 3
Near-ones, Home rehabilitation N = 4	R: 0-6, M: 1.58	R: 4-61, Mode 50	R: 15-90, M: 31	R: 1- 4, M: 2	R: 1-4, M: 3
Near-ones (both subgroups)	R: 0-6, M: 1.37	R: 4-61, Mode 54	R: 15-90, M: 73.83	R: 1- 4, M: 2	R: 1-4, M: 3

(Range: R, Mean: M **:** A: 15-30 min, B: 30-60 min, C: 60-90 min, D: over 90 min **:** 0=very poor, 1=poor, 2=acceptable, 3=good, 4=very good).
One person missing from M2 in Persons with PD, Gym rehabilitation subgroup.
Table 1: Physical activity and psychological well-being, per participant diaries.

Subgroup code / **Clinical Measures**	**Timed-up- and-go (TUG) 8-16 sec**		**Five Times Sit to Stand 14-38 sec**		**Berg Balance Scale**		**10 Meter Walk Test (10MWT),** preferred 0.96-1.6 m/sec		**10 Meter Walk Test (10MWT),** fast 1.5-1.9 m/sec		**Stride length (two steps) 1.04-1.46 m**	
	M1	**M2***	**M1**	**M2***	**M1**	**M2***	**M1**	**M2***	**M1**	**M2***	**M1**	**M2***
Persons with PD, Gym rehabilitation, N = 9	R: 5.81-29.35, M: 11.28	R: 4.56-19.65, M: 7.29	R: 8.72-32.34, M: 11.06	R: 8.0-27.31, M: 11.5	R: 31-56, M: 5.44	R: 38-56, M: 52.62	R: 0.46-1.11, M: 0.91	R: 0.67-1.41, M: 1.08	R: 0.60-2.02, M: 1.47	R: 0.89-2.56, M: 1.9	R: 0.62-1.24, M: 0.98	R: 0.82-1.42, M: 1.18
Persons with PD, Home rehabilitation, N = 9	R: 6.43-15.84, M: 10.79	R: 6.15-24.34, M: 9.77	R: 10.35-26.69, M: 16.67	R: 8.69-21.75, M: 13.82	R: 43-56, M: 50	R: 44-56, M:51	R: 0.57-1.21, M: 0.80	R: 0.75-1.41, M: 1.03	R: 0.99-1.91, M: 1.41	R: 1.19-2.22, M: 1.62	R: 0.79-1.33, M: 1.02	R: 0.90-1.47, M: 1.13
Persons with PD (both subsamples)	M: 10.85	M: 9.04	M: 15.63	M: 12.72	M:50.22	M: 51.76	M: 0.86	M: 1.06	M: 1.44	M: 1.75	M: 1.00	M: 1.16
Near-ones, Gym rehabilitation, N = 3	R: 6.75-8.84, M: 7.65	R: 5.6-6.5, M: 6.21	R: 10.97-14.31, M: 12.92	R: 8.66-9.47, M: 9.01	R: 51-56, M: 53	R: 55- 56, M: 55.66	R: 0.78-1.07, M: 0.93	R: 1.04-1.20, M: 1.14	R: 1.5-1.66, M: 1.6	R: 1.75-1.86, M: 1.79	R: 0.99-1.22, M: 1.07	R: 1.20-1.29, M: 1.24
Near-ones, Home rehabilitation, N = 4	R: 6.25-7.75, M: 6.64	R: 5.22-12.35, M: 7.35	R: 10.53-16.60, M: 13	R: 8.47-20.40, M: 12.43	R: 52-56, M: 55	R: 52-56, M: 55	R: 0.91-1.73, M: 1.28	R: 0.59-1.58, M: 1.17	R: 1.37-1.96, M: 1.76	R: 0.75-2.30, M: 1.71	R: 1.10-1.43, M: 1.25	R: 0.82-1.46, M: 1.19
Near-ones (both subsamples)	M: 7.08	M: 6.86	M: 12.98	M: 10.96	M: 4.14	M: 55.28	M: 1.13	M: 1.16	M: 1.69	M: 1.47	M: 1.17	M: 1.21

Berg Balance Scale: weak: 0-20, moderate: 21-40, good: 41-56**;** (Range: R, Mean: M).
Table 2: Clinical measurements before (M1) and after (M2) an eight-week intervention.

Subgroup code / Sum scores	Mobility		ADL		Emotional well-being		Stigma		Social well-being		Cognitive well-being		Communicative well-being		Bodily discomfort	
	10 items		6 items		6 items		4 items		3 items		4 items		3 items		3 items	
	M1	M2	M1	M2	M1	M2	M1	M2	M1	M2	M1	M2	M1	M2	M1	M2
PD/Gym, N = 9	R: 0-78, M: 3.22	R: 0-45, M: 4.55	R: 4-33, M: 8.22	R: 0-29, M: 5.88	R: 4-38, M: 4.66	R: 8-29, M: 8.55	R: 0-44, M: 1.22	R: 0-38, M: 1.22	R: 0-38, M: 3.03	R: 0-25, M: 7	R: 8-38, M: 21.50 (One Missing)	R: 13-38, M: 21.11	R: 0-32	R: 0-42, M: 15.75 (One Missing)	R: 17-50, M: 29.25 (One Missing)	R: 8-50, M: 1.55
PD/Home, N = 9	R: 0-80, M: 27.11	R: 0-75, M: 5.22	R: 0-67, M: 7.44	R: 0-67, M: 7.44	R: 0-75, M: 1.77	R: 0-67, M: 7.25	R: 0-44, M: 7.88	R: 0-38, M: 1.22	R: 0-25, M: 7.88	R: 0-17, M: 5.11	R: 13-50, M: 26.88	R: 13-63, M: 26.66	R: 0-58, M: 5.88	R: 0-58, M: 22.22	R: 0.42, M: 20.55	R: 0-75, M: 2.22
PD (both subgroups)	R: 0-80, M: 25.16	R: 0-75, M: 9.88	R: 0-67, M: 2.83	R: 0-67, M: 1.66	R: 0-75, M: 3.22	R: 0-67, M: 7.66	R: 0-44, M: 4.55	R: 0-38, M: 1.22	R: 0-38, M: 0.46	R: 0-38, M: 6.05	R: 8-50, M: 24.35	R: 13-63, M: 23.88	R: 0-58, M: 1.71	R: 0-58, M: 19.17	R: 0-50, M: 24.64	R: 0-75, M: 6.88
N-O/Gym, N = 3	R: 0-2.5, M: 0.83	R: 0-2.5, M: 0.83	R: 0-0, M: 0	R: 0-0, M: 0	R: 8-38, M: 9.66	R: 0-25, M: 2.66	R: 0-0, M: 0	R: 0-0, M: 0	R: 0-25, M: 8.33	R: 0-17, M: 5.66	R: 5-19, M: 14.66	R: 13-13, M: 13	R: 0-17	R: 0-0, M: 0	R: 25-50, M: 33.33	R: 25-25, M: 25
N-O/Home, N = 4	R: 2.5-33, M: 10.75	R: 0-63, M: 17.75	R: 0-4, M: 2	R: 0-8, M: 4	R: 0.29, M: 14.5	R: 0-25, M: 12.5	R: 0-6, M: 1.5	M: 0-0, M: 0	R: 0-33, M: 8.25	R: 0-17, M: 6.25	R: 0-25, M: 9.25	R: 0-13, M: 4.75	R: 0-16, M: 4	R: 0-8, M: 2	R: 8-50, M: 31.25	R: 0-33, M: 8.75
N-O (both subgroups)	R: Max, M: 6.5	R: 0-75, M: 10.5	R: 0-4, M: 1.14	R: 0-8, M: 2.28	R: 0-38, M: 6.71	R: 0-25, M: 2.57	R: 0-6, M: 0.85	R: 0-0, M: 0	R: 0-33, M: 8.28	R: 0-17, M: 6	R: 0-25, M: 11.57	R: 0-13, M: 8.28	R: 0-17, M: 4.71	R: 0-2, M: 1.14	R: 8-50, M: 32.14	R: 0-33, M: 1.32

Table 3: PDQ-39 on sum variable levels per subgroup, before and after rehabilitation.

When comparing the subgroups' PDQ-39 scores before the intervention (M1; PD/Gym to PD/Home, N-O/Gym to N-O/Home), mobility for both PD subgroups was seen to be homogenous, but differences were seen regarding all other domains (Table 3). The PD/Home subgroup more often reported problems regarding ADL (mean 27.44), emotional well-being (21.77), stigma (17.88), social (7.88), cognitive (26.88) and communicative well-being (25.88), indicating that they more often had problems with ADL functions and health-related QoL. The PD/Gym subgroup more often reported problems regarding bodily discomfort (29.25). When comparing differences between the N-O subgroups before the intervention (M1), the N-O/Home subgroup more often reported problems regarding mobility (10.75), while the N-O/Gym subgroup more often reported problems regarding emotional well-being (19.66), cognitive well-being (14.66) and bodily discomfort (33.33). Again, due to small sample sizes the significance tests between groups could not be analyzed.

When comparing the subgroups' PDQ-39 scores before and after the intervention (M1 to M2; internal, within-subgroup comparison), both improvements and reversals were seen. For all subgroups, ADL and cognitive well-being scores were nearly the same at M1 and M2. At M2, the PD/Gym subgroup more often reported problems regarding bodily discomfort (31.55), but less often reported problems regarding mobility (14.55), ADL (15.88), emotional (18.55), social (7.0) and communicative well-being (15.75). The PD/Home subgroup reported slightly more problems with bodily discomfort (22.22), but less often reported problems regarding emotional well-being (17.25), stigma (11.22), social (5.11) and communicative well-being (22.22). The N-O/Gym subgroup did not report more problems for any domain, but instead less often reported problems regarding emotional (12.66), social (5.66) and communicative well-being (0.00) and bodily discomfort (25.00). The N-O/Home subgroup more often reported problems regarding mobility (17.75) and ADL (4.00), but less often reported problems regarding cognitive well-being (4.75) and bodily discomfort (18.75).

Discussion

The aim of this paper was to describe the development of a person-centered, interactive, systematic, effective rehabilitation intervention for persons with Parkinson's and their near-ones, and outcomes of a pilot study. The project was initiated by some persons with PD and thereafter, as recommended [15,16], developed and conducted in intense collaboration: between persons with PD, near-ones and an inter-professional group (registered nurses, a physiotherapist, digital/virtual healthcare system experts, academic researchers). Public and patient involvement [23], the principles of human-centered co-design [24] and person-centeredness [17-20] were all used to help create a foundation for the pilot intervention. The research group decided to focus on an active physical lifestyle, through which PD symptoms can be alleviated and functional capacity maintained or improved [1]. Furthermore, the psychosocial and cognitive aspects of rehabilitation were included [9], seen in the intervention as supporting persons with PD and their near-ones in engaging in physical activity in a group (gym-rehabilitation subgroups) or at home with someone (home-rehabilitation subgroups) and as measuring participants' perceived psychosocial well-being and health-related QoL [11-13] before and after the rehabilitation intervention [14].

A total of 25 participants participated in the pilot intervention. Of these, the majority were persons with PD (n=18), male aged 55 or older, with early- or mid-stage PD. This makes the sample relevant in relation to PD incidence and prevalence internationally [c.f. 1,2, 6] and witnesses for the feasibility of recruitment of participants with PD. Participation was voluntary and based on participants' intrinsic motivation [2] instead of objective PD stage [11]. In this pilot study, participants' own perceptions of functional capacity and psychosocial well-being was in focus instead of number of years since diagnosis, medication, or other illnesses. Both PD subgroups had already before the intervention (M1) experienced limitations in ADL and health-related QoL, which indicates that all the participants with PD were in immediate need of rehabilitation [cf. 4,7,8]. Especially the PD/Home subgroup showed functional limitations and poor health-related QoL at M1 when compared to the PD/Gym subgroup: mobility (27 vs. 23), ADL (27 vs. 18), stigma (18 vs. 11), cognitive (27 vs. 22) and communicative well-being (26 vs. 17.5). However, at M1 the PD/Gym subgroup reported more problems with other domains than the PD/Home subgroup: emotional (25 vs. 22) and social well-being (13 vs. 8) and bodily discomfort (29 vs. 20.5). The PD/Gym participants might perhaps have chosen group activity in an attempt to improve these domains. Participants in the PD/Gym subgroup engaged in physical activity 1-5 times per day (mean 1.48), and the typical length of physical activity was about 44 minutes. Participants in the PD/Home subgroup (n=9) also engaged in physical activity 1-5 times per day (mean 1.08), but the typical length of physical activity was about 28 minutes. Psychological well-being after physical activity even differed between these subgroups. At M2, the PD/Gym subgroup showed a mean of 3 and the PD/Home subgroup showed a mean of 4, even though the PD/Home subgroup exercised mostly alone (80%). It might be the physical activity itself and not the social context that affects perceived psychological well-being [cf. 11].

After the intervention (M2), better outcomes for all clinical measurements were seen for both PD subgroups, and the 10MWT was normal. The PD/Gym subgroup reached overall slightly better outcomes than the PD/Home subgroup. This may be due to better functional capacity prior to inclusion in the study, the presence of a physiotherapist in the gym setting, or the social aspects of group rehabilitation. Regarding health-related QoL, both PD subgroups

reported better emotional, social and communicative well-being at M2 [cf. 12-14]. Among others, the PD/Gym subgroup less often reported problems regarding mobility and ADL, and the PD/Home subgroup less often reported problems regarding stigma. Still, both PD subgroups more often reported bodily discomfort. This could be due to a lack of awareness of own physical capacity (or limitations) prior to intervention period or can be attributed to self-comparison with other participants during the intervention, especially in gym-group, or incorrect self-reporting.

Seven participants were near-ones (n=7.38%), and of these the majority were female (88%), elderly (mean 71.5 years) spouses of persons with PD. Of those invited to join the project, ten near-ones declined to participate. Out of respect for their autonomy we did not document the reasons for their refusal, nor did we document the eventual medication or illnesses of those near-ones who participated. We merely sought the inclusion of near-ones in this intervention, because of the person-centered perspective we employed [18-20] and the fact that near-ones are not usually included in PD rehabilitation [9]. The inclusion of the spouses of persons with PD is vital to safe [6] and continuous rehabilitation [22], because they assist with reminders and act as companions and/or assistants.

Both N/O subgroups already before the intervention (M1) experienced decreased functional capacity and health-related QoL. For the majority of clinical measurements participants barely managed normal reference values, with the exception of the BBS, for which they displayed good results. They reported problems regarding emotional, social and cognitive well-being as well as bodily discomfort. Such results may be related to normal aging (near-ones were older than their spouses with PD, mean 71.5 years) or to the chronic disorder that their partners had, due to which the near-ones as unofficial family caretakers might feel sometimes physical or emotional exhaustion. Furthermore, PD in a family may cause some social withdrawal [7,8] affecting the social well-being. Still, the near-ones here did not report stigma.

At M1, the N-O/Home subgroup reported significantly more problems with mobility than the N-O/Gym subgroup (11 vs. 0.8). Participants in the N-O/Gym subgroup engaged in physical activity 0-2 times per day (mean 1.10), and the typical length of physical activity was about 42 minutes. Participants in the N-O/Home subgroup engaged in physical activity 0-6 times per day (mean 1.58), and the typical length of physical activity was about 31 minutes. Whether physical activity had any impact on psychological well-being differed between these subgroups; between M1 and M2, the N-O/Gym subgroup saw no change (M1: 3, M2: 3), while the N-O/Home subgroup saw slight change (M1: 2, M2: 3). Both N/O subgroups exercised mostly alone (80% and 78%), which might be due to social isolation or a desire to be alone.

After the intervention (M2), the N-O/Gym subgroup had better outcomes for all clinical measurements, especially the Five Times Sit to Stand, the 10MWT and the SL. In contrast, the N-O/Home rehabilitation group had marginally poorer clinical outcomes at M2. This may indicate that these participants would have benefited from individual instruction and feedback during physical activity, i.e., a more person-centered approach [cf. 18-20]. Regarding health-related QoL, the N-O/Gym subgroup reported better emotional, social and communicative well-being at M2, while the N-O/Home group reported better cognitive well-being but more often reported problems regarding mobility and ADL. This may be related to a new awareness of own physical resources and/or limitations, stemming from the clinical measurements and diary. Both N/O subgroups less often reported bodily discomfort at M2 than M1, which we attribute to increased practice and positive bodily self-awareness.

This study has some limitations: the study subsamples were small, especially for near-ones, which negatively affected the choice of statistical analyses and interpretation of results, as well as its´ external validity. During the next research phase, the same rehabilitation intervention will be implemented in a larger geographical area and in larger samples (200-300 per subgroup) making advanced statistical analyses possible. Additionally, the time at which clinical measurements are made will be recorded, because even those with optimal medical PD management experience varied daily function. Furthermore, more demographic data variables will be collected, including other diagnoses, medication, and perceived motivation.

Conclusion

The PISER rehabilitation intervention used here was seen to be person-centered, systematic, feasible and effective – when individual differences were acknowledged. All participants maintained or developed their functional capacity, psychosocial well-being and certain aspects of health-related QoL. We saw that an eight-week rehabilitation intervention can positively impact self-management and functional capacity, prevent inactivity and fall risks, and delay PD-related or other onset of activity limitations through improvements in gait (TUG, Five Times Sit to Stand, 10MWT, SL) and QoL (emotional, social, cognitive and communicative well-being). This was especially seen regarding group-based rehabilitation, where social well-being is promoted and when an instructor is present to provide person-centered instructions and feed-back or when a person him/herself engages in continuous, goal-oriented self-rehabilitation. Also, a daily 30-minute period of physical activity appears to improve clinical and subjective outcomes more than shorter daily periods.

While gym-based rehabilitation appeared to be slightly more effective than at-home rehabilitation, one should not disregard intrinsic motivation. Bio-physiological and environmental factors, including attitudes and support from others, and personal factors such as age, education, experiences, preferences, motivation and co-morbidity affect functional capacity [2]. Limited mobility can lead to poorer ADL capacity, stigma, or decreased cognitive or communicative well-being, resulting in increased risk for social isolation and lack of self-rehabilitation, which negatively affects functional capacity and QoL. It is vital that healthcare professionals and clients together analyze and discuss the meaning of physical activity and self-rehabilitation in relation to these functional and psychosocial issues.

Even bodily discomfort was seen to be an important component that affects functional capacity. We saw that bodily discomfort can act as a catalyst for physical activity or can be the result of self-analysis stemming from increased physical activity, self-comparison with others, or the keeping of a diary. Healthcare professionals should discuss bodily discomfort with clients, and seek to encourage clients to engage in future-oriented thought through use of, e.g., a diary or a digital device, and should provide instruction or suggestions for choosing from the different physical activities as needed. Lastly, to be truly person-centered, rehabilitation should always consist of more than physical rehabilitation activities, it should encompass psychosocial and cognitive components as well.

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References

1. Current care guidelines: Parkinson's disease (2018).
2. Keus SHJ, Munneke M, Graziano M, Paltamaa J, Pelosin E et al. On behalf of the Guideline Development Group. European

physiotherapy guideline for Parkinson's disease (2014) KNGF/ParkinsonNet, Netherlands.
3. Rizek P, Kumar N and Mandar SJ. An update on the diagnosis and treatment of Parkinson disease (2016) CMAJ 188: 1157-1165. https://doi.org/10.1503/cmaj.151179
4. Hariz G and Forsgren I. Activities of daily living and quality of life in persons with newly diagnosed Parkinson's disease according to subtype of disease, and in comparison to healthy controls (2011) Act Neur Sca 123: 20–27. https://doi.org/10.1111/j.1600-0404.2010.01344.x
5. Ebben J. How to make patient included innovations successful. Upgraded Life Festival, Helsinki.
6. Gisbert R and Schenkman M. Physical therapist interventions for Parkinson Disease (2015) Phys Ther 95: 299-305. https://doi.org/10.2522/ptj.20130334
7. Balash Y, Korczyn AD, Knaani J, Migirov AA and Gurevich T. Quality-of-life perception by Parkinson's disease patients and caregivers (2017) Act Neur Sca 136: 151-154. https://doi.org/10.1111/ane.12726
8. Kelly DH, McGinley JL, Huxham FE, Menz HB, Watts JJ, et al. Health-related quality of life and strain in caregivers of Australians with Parkinson's disease: An observational study (2012) BMC Neur 12: 57-62. https://doi.org/10.1186/1471-2377-12-57
9. Vaartio-Rajalin H, Rauhala A and Fagerström L. Person-centered home-based rehabilitation for persons with Parkinson's disease – a scoping review (2019) International Journal of Nursing Studies 99: 103395. https://doi.org/10.1016/j.ijnurstu.2019.103395
10. Hoehn MM and Yahr MD. Parkinsonism: onset, progression, and mortality (2001) Neurology 57: 11-26.
11. Hedman M, Pöder U, Mamhidir A-G, Nilsson A, Kristifferzon M-L et al. Life memories and the ability to act: the meaning of autonomy and participation for older persons when living with chronic illness (2015) Sca J Car Sci 29: 824–833. https://doi.org/10.1111/scs.12215
12. Nicoletti A, Mostile G, Stocchi F, Abbruzzese G, Ceravolo R, et al. Factors influencing psychological well-being in patients with Parkinson's disease (2017) PLOS ONE 15. https://doi.org/10.1371/journal.pone.0189682
13. Ylikoski A, Martikainen K, Sieminski M and Partinen M. Sleeping difficulties and health-related quality of life in Parkinson's disease (2016) Act Neur Sca 135: 459-468. https://doi.org/10.1111/ane.12620
14. Doga VB, Koksal A, Dirican A, Baybas S, Dirican A, et al. Independent effect of fatigue on health-related quality of life in patients with idiopathic Parkinson's disease (2015) Neur Sci 36: 2221–2226. https://doi.org/10.1007/s10072-015-2340-9
15. Ferrazzoli D, Ortelli P, Zivi I, Cian V, Urso E, et al. Efficacy of intensive multidisciplinary rehabilitation in Parkinson's disease: a randomised controlled study (2018) J Neurol Neurosur and Psych 89: 828-835. https://doi.org/10.1136/jnnp-2017-316437
16. Earhart GM and Williams AJ. Treadmill Training for Individuals with Parkinson Disease (2012) Phys Ther 92: 893-897. https://doi.org/10.2522/ptj.20110471
17. Institute of Medicin. Crossing the quality chasm: A New Health System for the 21st Century (2016) National Academy of Sciences.
18. Ekman I, Swedberg K, Taft C, Lindseth A, Norberg A, et al. Person-centered care-ready for prime time (2011) Eur Journal of Card Nur 10: 248-251. https://doi.org/10.1016/j.ejcnurse.2011.06.008
19. McCormack B and McCance TV. Development of a framework for person-centred nursing (2006) J of Adv Nur 56: 472-479. https://doi.org/10.1111/j.1365-2648.2006.04042.x
20. Kitwood T. Dementia reconsidered: the person comes first (1997) Open University Press, United Kingdom.
21. Vaartio-Rajalin H and Fagerström L. Professional care at home: patient-centeredness, interprofessionality and effectivity? A scoping review (2018) Health Soc Care Comm 27: e270-e288. https://dx.doi.org/10.1111/hsc.12731
22. Moldovan AA and Dogaru G. Increasing functionality and the quality of life through medical rehabilitation in patients with Parkinson's disease (2014) Balneo Res Jour 5: 193-198. https://doi.org/10.12680/balneo.2014.1077
23. INVOLVE. What is public involvement in research? (2019).
24. Kachirskaia I, Mate KS and Neuwirth E. Human-centered design and performance improvement: better together (2018).
25. Tuulaniem J. Service design (2013) Talentum Oyj.
26. Jenkinson C, Fitzpatrick L, Peto V, Greenhall R and Hyman N. The PDQ-8: Development and validation of a short-form Parkinson's disease questionnaire (1997) Psy Hea 12: 805-814. https://doi.org/10.1080/08870449708406741
27. Orsmond G and Cohn ES. The distinctive features of a feasibility study: objectives and guiding questions (2015) OTJR (Thorofare N J) 35: 169-177. https://doi.org/10.1177/1539449215578649